

Abortion and euthanasia of Down's syndrome children – the parents' view

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Author's abstract

A study of 78 parents of Down's syndrome children shows that, while most were in favour of abortion for a handicapped fetus, they were divided equally on whether euthanasia (no distinction made between active and passive euthanasia) was an acceptable practice. Only a third considered an average Down's syndrome child could be a suitable candidate for euthanasia. While parents argued that the degree of handicap of the child was the crucial factor in making this decision, in fact the social class of the parents themselves was the only variable which was statistically significantly related to their opinions. Differences arose from the parents' lack of agreement on what constituted a sufficiently severe handicap.

Introduction

The dilemma of how actively to intervene to keep a severely handicapped child alive is one which has always faced doctors and midwives but it has only recently become a debate for wider, popular discussion. Increasingly parents of handicapped children are being consulted openly about this decision although, inevitably, few will have had any personal experience of life with a handicapped child and will be ill-equipped to make a well informed decision. This paper gives the opinions on abortion and euthanasia of people who have had this first-hand experience: parents of Down's syndrome children.

Method

In 1972 a study (unpublished) was made of Down's syndrome children born in the years 1964-66 and living with their parents in South Wales. Two new studies based on this work were carried out in 1981. For the re-study contact was again made with all Down's syndrome children living with their parents and born in 1964-66 and, in addition, a new sample of all Down's syndrome children born in the years 1973-75 was also studied. Considerable effort was made to ensure that

the total population was included. Eighty-four families were contacted. There were four refusals. Opinions given here are those of the main carer: in most cases this was the mother but there were three fathers, one stepmother, an adoptive mother and one sister and one grandmother who were responsible for care. Two were not asked about abortion and three were not asked about euthanasia, on what might be called compassionate grounds.

In 1972 selected parents were asked about their opinions about both abortion after amniocentesis and about euthanasia in order to test reaction. Results were encouraging and indicated that parents were willing to discuss these topics and consequently the subjects were incorporated routinely into the 1981 study. Mothers were asked: 'How do you feel about abortion after an amniocentesis test has shown a mother is carrying a handicapped child?' The question on euthanasia was obviously more sensitive and one clinician suggested that this line of enquiry should not be pursued. However, the decision to pursue it had been made and the intended question concentrated on how far severely handicapped babies, who were also ill, should be kept alive. In the event, on April 3, 1981 and six days before the first interview, Dr Arthur was committed for trial for the murder of John Pearson, a three-day-old Down's syndrome baby who had been rejected by his parents. The opportunity was taken to introduce the topic in a more natural and impersonal fashion and the question was rephrased: 'Don't answer this if you can't, or don't want to but I wonder if you have given any thought to the doctor in Derby who has been accused of murdering a three-day-old mongol/Down's syndrome baby?' This was used simply as a way of introducing the topic rather than in order to discuss the case. Follow-up questions varied with the answer given but were intended to determine firstly, whether parents felt that all the lifesaving efforts which are routinely extended to normal babies should be given to all handicapped babies and, for the parents who did not feel this should be so, whether they felt an average Down's child was sufficiently handicapped to be allowed to die in this way. There were several reasons why parents were not pressed on the distinction between killing a baby and allowing it to die. The central issue was deemed to be whether parents

Key words

Down's syndrome abortion; Down's syndrome euthanasia; allowing to die; euthanasia; abortion.

accepted the notion that it was better for some children to die rather than live and whether it was a legitimate choice to take practical steps to further this point of view. It is arguable that there is little moral difference between actively killing a child and passively allowing one to die (1) and this was the approach which was adopted here. Also the topic was one which was essentially incidental to the main aims of the study and was raised at the end of a long interview which had usually lasted at least two to three hours. In the circumstances consideration of the practical niceties of how to ensure the death of a child, not unlike the one who had been under discussion, seemed inappropriate. In addition, pressing the question would have raised more uncertainty and would undoubtedly have distressed a few parents. Consequently the term euthanasia is used throughout this paper without implying a distinction between active or passive euthanasia unless this is specifically stated. Questions which confronted parents with considering their own child in relation to euthanasia were avoided. Two further variants are worth noting: three respondents broached the topic themselves during the main interview and so rendered the question at the end redundant and, secondly, the *R v B(Minor)* case in which Alexandra, a Down's syndrome baby, was made a ward of court because her parents refused to consent to a lifesaving operation for her, took place towards the end of the fieldwork. This could have influenced the final six interviewees since the publicity and discussion surrounding this case was far greater than that which had attended Dr Arthur's committal for trial.

Inevitably the population is not wholly comprehensive. Since the children were all living at home it excludes parents who rejected their children outright and never had them home at all. However, parents of the older children were given little option on alternatives to home care and the care available at that time tended to be considered unacceptable anyway. These mothers frequently mentioned the lack of choice:

'They didn't ask me if I wanted her.'

'They said "Well you can't leave him here." (in the maternity hospital).'

For the younger children, however, fostering was a possibility and a few babies in the younger sample were fostered until mothers became reconciled to taking them home. Lorber (2) states that until recently parents of spina bifida children were barely consulted over treatment of their babies. Certainly in this population choices over treatment usually were not given to parents of either older or younger children although some would undoubtedly have grasped this opportunity. Typical of the ways mothers spoke of post-natal events were:

'They told me three hours later (after the birth) that they might have to operate on him because he couldn't go to the toilet.'

'I did wonder why they were trying so hard to keep him alive.'

In fact, far from suggesting that extraordinary efforts need not be taken to keep the child alive, two mothers of younger children felt paediatricians actively encouraged them to bond with their rejected babies. Consequently, while these opinions are those of parents who have experienced life with a Down's syndrome child, these parents cannot speak with personal knowledge of having made, or been confronted with these decisions. Indeed, had the choices been available to them, a proportion of these parents would not have been in this population at all.

Results

OPINIONS ON ABORTION AFTER AMNIOCENTESIS

Parents were asked what they felt about abortion of a Down's syndrome fetus after amniocentesis. Sixty of the 78 parents (77 per cent) asked agreed with an abortion in these circumstances although five of these mothers went on to say that this would not be their decision for themselves but they would not disapprove of abortion in these circumstances for other people. The mothers of the younger children were more ready to accept abortion than those of the older children (85 per cent compared with 63 per cent) presumably reflecting the more widespread knowledge about, and acceptance of, abortion among younger women. Unlike in 1972 all seemed prepared to accept that the test would give an accurate result. It is worth recording the statement about abortion of one mother of a six-year-old child which illustrates the inevitable difficulties of making decisions without full knowledge:

'If I hadn't already had one it would be an easier decision but I've had W and she is classed as handicapped. But she's lovely, she seems as normal as can be, so I couldn't have an abortion after W, but if I hadn't had her, my idea of *being* handicapped would be different.'

OPINIONS ON EUTHANASIA

Taking both samples together, 37 (48 per cent) of the 77 parents asked about euthanasia were prepared to accept the idea that not all handicapped children should be kept alive at all costs but many qualified their approval in the following ways. Some clearly believed that there was an important moral difference between acts of commission and acts of omission when the intention was for the child to die. Five specifically said that actively killing the child was wrong; one or two implied that a lingering death (especially if it involved starving the child) was unacceptably cruel. About three-quarters of the 37 gave some degree of support to doctors who helped a severely handicapped child to have a peaceful death, but since this was not an issue on which parents were pressed, the figures should be treated with caution. Concerning Dr Arthur, one father said 'I admire the man' and another father

praised his courage. Four or five mothers said that they felt sympathy with and supported parents who took these painful decisions while they added that it would not have been possible for them to do likewise. Overwhelmingly, however, the commonest proviso expressed by almost half of the 37 and possibly felt by more, was concerned with the degree of handicap of the child. For children very severely handicapped like 'cabbages' or 'vegetables where they don't know who or what they are', euthanasia was considered a legitimate choice but it was also apparent that many parents would not accept that a Down's syndrome child, without additional problems, could be considered as 'very severely handicapped'. In fact only 33 per cent of parents were prepared to concede that an average Down's syndrome child might fall into this category and even then, while this rather offensive question was not pressed, most would probably not have included their own child in this group. In this borderline area such decisions were essentially subjective and this 33 per cent included parents who had children among the less severely handicapped. One father, whose child scored exceptionally well on tests, said 'Look at M, it's not a full life, there are a lot of problems'. In contrast, of the parents of the 12 children who scored more than one standard deviation below the mean on the Gunzburg Progress Assessment Chart 1, which is a measure of social competence, only one parent considered Down's syndrome children 'very severely handicapped' for these purposes. Clearly the parents would find it difficult to reach any consensus on what constituted very severe handicap. Indeed, parents were not always clear themselves what they meant by very severe handicap.

These figures conceal a very wide range of answers which were given on this topic. The most vehement replies in favour of euthanasia came from the mothers of older children, a few of whom were in no doubt about their feelings:

'If I knew as I know now I'd have euthanasiaed (*sic*) her. It's cruel for me and cruel for her. There's no life for me while she's here and none for her . . . it's not a bit of good, the country's better off without them . . . a handicapped mind and a handicapped body, it's cruel. When a dog's injured you put it down.'

In 1972 one of the mothers said:

'Oh if I could have got away with it I would have neglected him because I was so fed up and tired more than anything, so if I could have got away with it I would have neglected him. I'm sorry I didn't in a way. You've got to be honest – they are a tie for the rest of your life . . . there's not going to be any freedom at all.'

Seen again in 1981 she had not altered her opinion.

Two mothers of teenage children put the opposite view equally strongly.

'I think it's awful. I wouldn't have liked it to happen to mine once it was born.'

(mother of two Down's syndrome children)

'I think it's wrong. Someone could have done it to (my daughter) but she's come on exceptionally well and we'd have missed a lot. It's the same as murder of an ordinary child – no question with any handicap, it's the taking of life. How can you tell at that age?'

Asked whether she felt that, where the degree of handicap could be determined to be severe, euthanasia was acceptable she replied:

'I still wouldn't agree. It's like Hitler and a super race. There's a reason for us all.'

The replies of the younger mothers again reflected the whole range of opinions although no one showed the strength of negative feelings displayed by some of the mothers of the teenage children.

Differences between the two samples do not reach statistical significance although there was a trend for parents of the younger children to be less ready to consider uncomplicated Down's syndrome children as candidates for euthanasia (22 per cent of the younger sample compared with 38 per cent of the older). On the general question of euthanasia for handicapped children, differences were small (56 per cent of the older group finding it acceptable compared with 48 per cent for the younger). There are several possible explanations of this difference. The greater possibility for parents of younger children to have their children cared for away from home has been mentioned already. Another, and more likely, explanation is concerned with the very different attitudes which now prevail towards Down's syndrome children. These days parents initially are usually given a more positive picture of the child's likely development and achievements and, in some cases, many support services are available for under fives (for example, home teaching schemes, nursery places and the attendance allowance). As a result parents on the whole are now much more optimistic about their children's futures.

A closer analysis of the sample shows that parents in higher social classes (3) are significantly more likely to consider euthanasia for very severely handicapped babies more acceptable than those in lower social classes (see Table 1).

It has been said that some of these parents, while supporting euthanasia for the severely handicapped, would not consider the average Down's syndrome child as a suitable candidate for euthanasia. Table 2 shows that it is the parents in social classes I and II and who support euthanasia for severely handicapped children, who are least likely to modify their position and consider Down's syndrome children as unsuitable candidates for euthanasia. When Down's syndrome children are discussed, there is little difference

Table 1:
Social class of parents and opinions on euthanasia for very severely handicapped children (% in brackets)

Social classes	In favour of euthanasia	Against euthanasia	Total
I and II	17 (68)	8 (32)	25
III (a and b)	15 (42)	21 (58)	36
IV and V	5 (31)	9 (56)	14
	37 (48)	38 (49)	75*

Goodman and Kruskal's gamma = .418 (15).

This produces a standardised normal deviate of 2.19 (Significant at the 5% level).

* Two mothers were undecided.

Table 2:
Social class of parents and opinions on euthanasia for average Down's syndrome children (% in brackets)

Social classes	In favour of euthanasia for Down's syndrome	Against euthanasia for Down's syndrome	Total
I and II	14 (56)	11 (44)	25
III (a and b)	8 (22)	28 (78)	36
IV and V	3 (21)	11 (79)	14
	25 (33)	50 (67)	75*

Goodman and Kruskal's gamma = .511 (15).

This produces a standardised normal deviate of 2.63 (Significant at the 1% level).

* Two mothers were undecided.

between the opinions of social classes III, IV and V. The difference between social classes I and II and the rest of the parents becomes more significant than when euthanasia for the severely handicapped only is considered.

In view of the fact that decisions made at birth are not reversible it seems relevant to discuss changes which occurred in mothers' opinions. At least five mothers resented the active steps which had been taken to preserve life for their own children and three mothers, who were now enthusiastic and loving parents, said they had wished for their children to die in the early months. Extreme changes in their views had taken place.

'I wanted her to die. The better she was getting the worse we were. Now she is my life. If I'd been given the choice she'd have gone.'

One mother's feelings had undergone a change in the opposite direction:

'I felt the opposite then (at the birth) . . . but if people had had a Down's syndrome child they'd feel differently too. It's all right for those who've never had one to say keep them alive. On the surface things don't look any different but in reality it's a continual strain. You don't show it outside.'

Only 30 parents gave their views on who should make these life and death decisions. Eighteen parents (60 per cent) felt that it was the parents' own decision and only five thought it was up to the doctors. A further five opted for a joint decision and two parents were not sure. Surprisingly, very many people spoke as if it was a private affair between parents and doctors, as if the child was a simple extension of its parents, although it is impossible to quantify this since the issue was not specifically raised. One stepfather said, referring to R v Arthur, 'It's not murder, because there was family permission'. Two mothers wished to be spared all responsibility:

'They should do it and not say – say the poor baby was ill and passed away.'

'If they're going to do anything it shouldn't be made known . . . I know it's shoving it all on the doctors but they're not so involved – it's impersonal to them . . . with us we'd have it for the rest of our lives, they'd go home and forget it. I still think with babies when they're born very handicapped and the parents don't want it – put it away. Then it's a mercy.'

The results indicate that it is not characteristics of the child (ie age and abilities) which primarily influence opinions. Rather more crucial is the social class of the

parents. Of those who would countenance euthanasia, parents of all classes believe that it is the degree of the child's handicap which is the paramount factor. There are disagreements, however, over the definition of severe handicap, with those in the lower social classes clearly showing a higher tolerance over what is an acceptable degree of handicap.

Discussion

The value of this research lies in the fact that it discovers the opinions of an unselected group of parents who have coped with their Down's syndrome children at home and who, it follows, have more personal experience of the consequences of our present laws on euthanasia than have lawyers, doctors or the general public. It must be considered what light this research throws on the present debate and how far parents agree or disagree with views currently mooted.

The problem of medical treatment for handicapped babies is not a new one. The *Glasgow Medical Journal* (4) in 1888 reported one surgeon who, discussing an anencephalous birth, regarded it as 'a question in ethics, whether in such cases the cord should not be left untied'. What is a new feature of the debate is that it is no longer private but one which, particularly in recent years, has become open. While Holt (5) questioned anyone's ability to make confident assessments on the quality of another's life, an editorial on abortion in the *British Medical Journal* (6) seemed to assume that doctors had the duty and right to do this and, presumably, the ability to distinguish between children and thus decide which ones should receive 'active treatment'.

'For the law does not seek to dictate other clinical decisions that, like recommending abortion, have moral overtones. Doctors are left free to make the best judgments they can when considering such difficult choices as whether or not to give active treatment to severely handicapped babies, or to patients with incurable terminal disease.'

If this was, indeed, a commonly held view then it has been considerably undermined since that date. Kennedy's Reith lectures in 1980 (7), and more recent legal interventions over parents' and doctors' decisions about the lives of Down's syndrome babies, have caused considerable controversy.

Much of the argument has centred on the fact that uncomplicated Down's syndrome children are not sufficiently handicapped to warrant this treatment. Certainly this was the view of the majority of parents in this population. Down's syndrome does, however, fall very clearly on the borderline of what is considered by parents and professionals to be severe handicap and what is not and this uncertainty among professionals has affected Down's syndrome children in the past. Problems have arisen in allocating allowances to Down's syndrome children, especially when new provisions are being introduced, because of this same

lack of agreement over the severity of the handicap (8,9,10). It is possible to speculate that recognition of this 'borderline' status of Down's syndrome was a factor in the selection of the Pearson infant by Life for action in that, had the subject been more grossly malformed, lay and professional support for the prosecution would possibly have been less. This study highlights the very real difficulties legislators would have in legalising euthanasia in that there is little agreement between parents on whether it is an acceptable practice at all and, if it is, where the line is to be drawn. The results demonstrate how impossible it would be to suggest any consistent course of action which would satisfy all parents. It has been shown that it is not necessarily parents of the most disabled Down's syndrome children who support euthanasia. Again, some parents in this sample felt resentment that they had been given no choice to deny treatment for their babies in the post-natal period. In contrast, an American study (11) reports that about two-thirds of 16 parents whose Down's syndrome children had had lifesaving treatment were resentful that the way treatment was discussed with them was, they felt, affected by the fact that the child was handicapped. Once the decision to treat had been made the care given was acceptable.

More patients in this study were ready to accept euthanasia for the more severely handicapped babies and the decision in *R v Arthur* would seem to imply that juries are likely to be sympathetic to doctors who make these decisions in good faith. Kennedy (12) argues that society could decide, if it wished, that these life and death decisions should properly be left to parents and doctors. No doubt there would be general agreement about the more extreme ends of the spectrum (though not total agreement) but it has been shown here that parents do not judge their Down's syndrome children on any objective criteria and it is likely that there would be a very large grey area. This would lead to giving different treatment to similar babies, simply because their parents and doctors held differing views. While the differences which exist between countries would probably be tolerated (13), differences *within* this country would probably not be regarded as satisfactory. Such variability in medical treatment would not be acceptable for normal babies except when it concerned comparatively trivial matters. The *British Medical Journal's* legal correspondent (14), relying on a definition of murder given by Lord Coke, suggests it could be argued that killing is only murder if the victim is a 'reasonable creature' but it seems likely that the definition of 'reasonable' in this context would result in the same lack of agreement. However, if any relaxation in the law were allowed, it is relevant to ask the degree of disability at which babies would be selected as suitable for their usual rights to be waived. Most of the parents in this sample would not regard Down's syndrome children as suitable, but equally, not including them would not be regarded as satisfactory by some and the considerable unhappiness

of these mothers would have to be taken into account. Similar conflicts would no doubt arise over severe physical, rather than mental, disability. It would also need to be considered at what stage after the birth the infant should resume normal rights (a particularly pertinent question in view of the fluctuations in feelings which mothers can experience in the post-natal period) and whether the issue would be re-opened if subsequent life-threatening situations arose. A further problem is that, in this sample, parents in social classes I and II are more likely to find euthanasia acceptable. We do not know whether or not this is true of the whole population of parents of handicapped children, but such parents are not only likely to be articulate but are also likely to share the class values of those responsible for formulating legislation and for implementing it.

Conclusion

This study demonstrates the impossibility of reaching any universally acceptable decision about euthanasia for Down's syndrome children since legal action or inaction will equally lead to discontent and in whatever way the dilemma is resolved there will be dissatisfaction. It is apparent that no change in the law is contemplated at present and presumably doctors are left walking a shaky tightrope deciding how active they are permitted to be in 'allowing' handicapped babies to die. Forbidding any form of euthanasia, active or passive, would lead to the preservation of grossly deformed and unresponsive children, who were possibly in pain, and to consequent extreme unhappiness of some parents and siblings. It should not be assumed, without evidence, that fostering the child (even if foster parents were available) would always remove this unhappiness. Legal rejection of active or passive euthanasia implies a public as well as private interest in handicapped people and therefore ought surely to be matched by large expenditure in order to avoid providing services which give rise to shame and scandal. This needs to be balanced against the results of legalising euthanasia which would undoubtedly lead to variation in the use of lifesaving treatment for children in morally indistinguishable categories. There would also be parents who, whatever decision they made, would come to regret it. Another important danger is that parents who elected to keep their children might be subjected to disapproval, rather than sympathy, and even perhaps a subsequent reduction in funds and help since these parents could be deemed wilfully to have chosen their situation. The take-up for abortion has increased since the law has been liberalised and it is likely that, in the same way, euthanasia would become an increasingly attractive choice for parents of handicapped babies. Giving parents some limited degree of choice over what is, after all, the quality of their offspring would be regarded as sensible by some, but unacceptable and dangerous by others.

Acknowledgments

Thanks are due to the Joseph Rowntree Memorial Trust who funded the research, to the parents of the children who were interviewed and to colleagues in the Medical Sociology Research Centre, University College, Swansea.

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